

This research and report was initiated, funded and written by LEO Pharma UK. Allergy UK and UK healthcare professionals reviewed and contributed to the research and report. Allergy UK is working in collaboration with LEO Pharma to share the outputs of this report to improve healthcare support for people living with CHE.

AllergyUK



THE CHRONIC HAND ECZEMA PATIENT IMPACT REPORT



EXECUTIVE SUMMARY

Hand Eczema (HE) is a painful inflammatory skin condition that occurs across the hands and the wrists.^{1,2} It is a condition that can be caused by many different and complex contributing factors, and the clarification into subtypes can be controversial.³ HE has a lifetime prevalence of approximately 14% in the general population.⁴

Chronic Hand Eczema (CHE) is defined by the European Society of Contact Dermatitis guidelines as symptoms that last for more than three months, or relapses twice or more per year, meaning these individuals may be experiencing repeated cycles of flares that can then have an impact across many aspects of their lives.^{1,3}

Although hands are only 4% of the body area, there are challenges associated with CHE, due to the functionality and visible nature of the hands.¹ To explore the impact that this condition has on people's lives, a multi-disciplinary taskforce was created. This taskforce was initiated and funded by LEO Pharma and included representation from primary care, secondary care, and the charity Allergy UK.

CHE Taskforce



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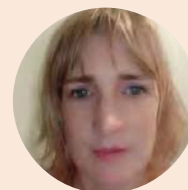
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LEO Pharma, with input from the CHE Taskforce, commissioned research with people living with CHE in the UK to identify their unique challenges and unmet needs. Five in-depth interviews were conducted, followed by an online survey of 152 people to explore issues across five areas, physical experience, psychosocial impact, quality of life and relationships, work and patient healthcare experience.

The research uncovered a significant physical and emotional impact, with CHE negatively affecting quality of life, work, and relationships. Half of the respondents experienced anxiety or anger due to their CHE, yet only 14% have been asked about the emotional impact of their CHE by any healthcare professional (HCP).

Additionally, people living with CHE reported delaying seeking help, experiencing the condition for a median of eight years before initially accessing healthcare support, most frequently due to not thinking their symptoms were severe enough or not wanting to make a fuss.

The findings identify a need for greater education for HCPs regarding CHE and more support for people living with suspected CHE, to seek healthcare support earlier.

KEY FINDINGS



strongly agree that having eczema on the hands is harder than other areas of the body because they're in constant use.

Half of people who live with CHE have experienced anxiety or anger, yet



only 14%

have been asked about the



emotional impact

by any healthcare professional.

“

I can't both my little boy regularly because of my hands and I feel really guilty as I feel like a bad mum. It also means that I get anxious about housework as my partner has to do more than me.

”



7 out of 10

said their CHE has some impact on their existing relationships or ability to build new ones.

Around 1/2 said their CHE influenced their career choice and yet

72%

state that they currently experience some impact on their current work or education due to their CHE.



People experience CHE for a median of 8 years

prior to seeing an HCP for the first time, with the most common reason for this delay was that they didn't think it was severe enough.

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RESEARCH DESIGN

This research was designed and carried out by Synergy Healthcare Research.

LEO Pharma would like to thank everyone who contributed to this research project, including Allergy UK and the CHE Taskforce. We would like to thank and recognise all the individuals living with CHE who shared their personal and healthcare experiences within this project.

SAMPLE

- **Phase 1:** Initial 60-minute qualitative interviews with five people living with CHE across the UK.
- **Phase 2:** The insight from Phase 1 and the CHE taskforce was used to develop a 15-minute online survey. This was completed by 152 people living with CHE across the UK. 50 recruited via panel, 102 accessing survey via Allergy UK communications.

RECRUITMENT CRITERIA FOR THE SURVEY

- Age 18+
- Experienced Chronic Hand Eczema for more than a year
- Previously seen an HCP in relation to hand eczema (GP and/or dermatologist/dermatology nurse)
- Used a medical treatment for hand eczema
- Hand eczema has an impact on aspects of life such as work/school, relationships, ability to carry out day-to-day tasks or socialising

DEMOGRAPHICS

- **Age:** Range 20-75; 22% aged 18-29, 37% aged 30-39, 18% aged 40-49, 23% aged 50+
- **Gender:** 79% female, 19% male, 2% prefer not to say
- **Location:** England 86%, Scotland 7%, Wales 5%, Northern Ireland 2%
- **Ethnicity:** 81% white (British/Irish/Other), 7% Asian/Asian British, 5% mixed descent, 3% black/black British, 5% other

Our research explored the following areas:



Physical experience & unavoidable triggers



Psychosocial impact



Quality of life & relationships



Impact on work



Patient healthcare experience



PHYSICAL EXPERIENCE & UNAVOIDABLE TRIGGERS

A high burden of itch and pain

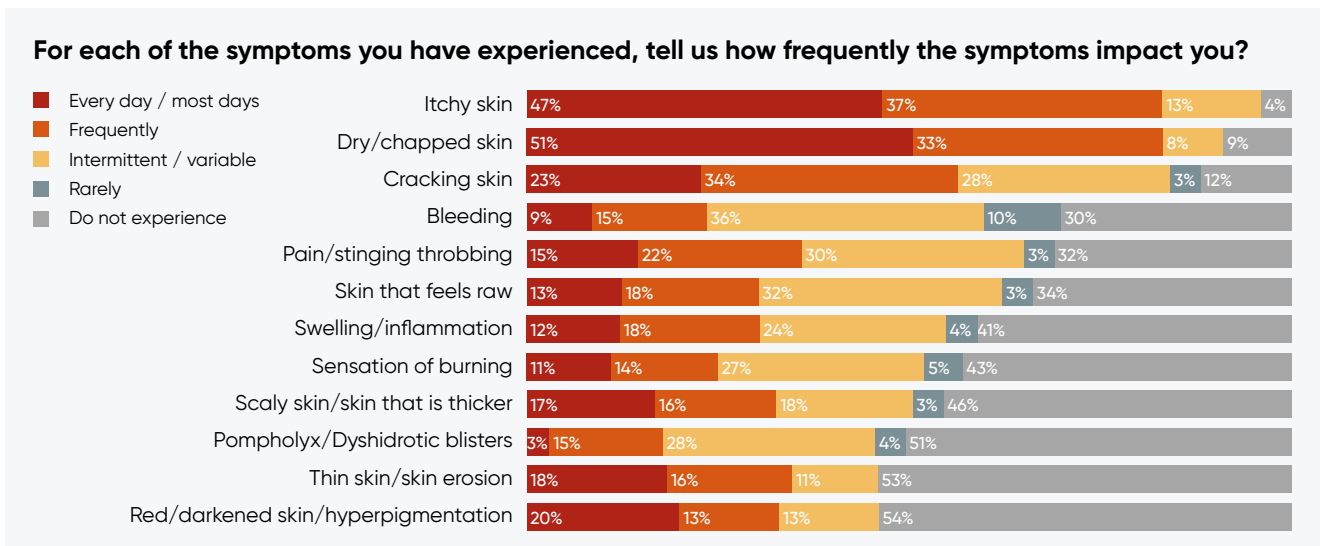
The respondents spontaneously described their physical experience of CHE as itchy, painful, dry, sore, burning, and cracked. They were invited to share descriptive prose to bring the experience of living with CHE to life:

“ It feels like **papercuts all over my hand** with all the little cracks and cuts. ”

“ My eczema feels like **I'm wearing gloves which are too small.** ”

When asked to select from a list of physical symptoms, most reported symptoms of itchy skin (96%), dry or chapped skin (91%) and cracking skin (88%), with over half sharing that they experience these symptoms either most days or frequently.

They reported experiencing periods of symptoms or worsened symptoms, known as flares, a median of eight times per year, lasting a median of nine days.



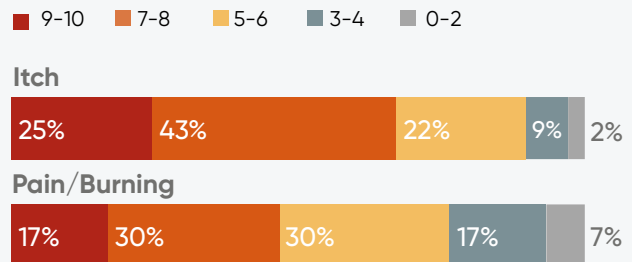
Consequently, the frequency of these CHE symptoms has an impact on people's lives. Survey respondents were asked to rate the extent to which itch and pain/burning impacts on their life on a scale of 0-10.

Respondents rated an average impact score of 7.2 out of 10 for itch and 6.2 for pain/burning.

CHE patients describe the itching as unbearable, impossible to satisfy and all they can think about.

On a scale of 0-10, to what extent does itch or pain/burning from your hand eczema impact on your life?

(0 = not at all and 10 = significant impact)



“ It's **like a drug addict** when they're itching to like get their next fix, I'm itching to itch. They're itching to get their next fix. I'm itching to get rid of it. They want to get rid of that like desperation for drugs, and I'm trying to get rid of the **desperation to itch.** That's genuinely how I look to myself. It's like, **what's wrong with me?** I don't know, **it's just a nightmare,** honestly. ”

Hands are a particularly challenging area of the body

Despite CHE being characterised by the frequency of symptoms across the hands and the wrists,^{1,2} the majority also experience eczema across other areas of their body.

It was identified that only 9% had eczema just on their hands. Across all the respondents, they reported a median of four body areas affected.

Despite almost all having eczema elsewhere on their body, the vast majority (94%) agreed to some extent that having eczema on their hands is harder than the rest of the body because they need to constantly use their hands, with 75% agreeing strongly.

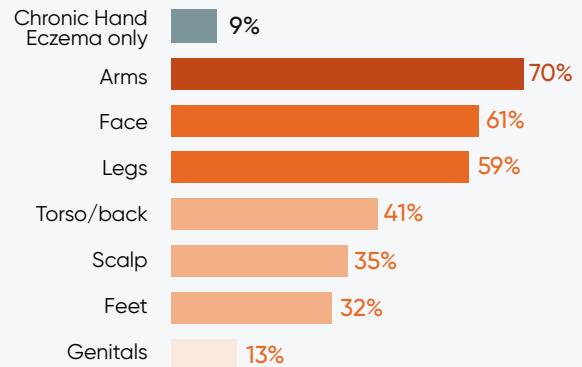
The triggers for CHE can be wide-ranging and complex,³ 94% agreed that their triggers for CHE were hard to avoid. For some people living with CHE it is difficult to avoid triggers such as hand soap, sanitiser, washing up liquid and cleaning products. Therefore, the most frequently reported impact was the ability for people to do their housework (73%).

One interview participant described avoiding washing up by using disposable paper plates and plastic cutlery whilst at university to avoid creating conflict with housemates in their shared kitchen space.

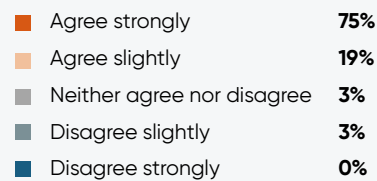
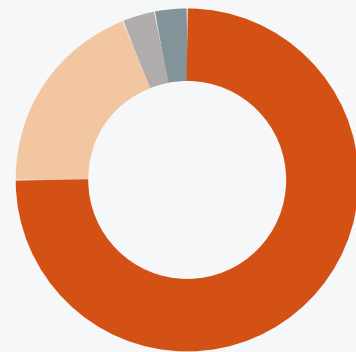
Respondents shared their common triggers including cleaning products, sweating, hot weather, cold weather, stress, grass, animal fur, dust and cooking. One individual shared the anxiety of constantly having to avoid their triggers:

“ **I'm frightened of doing things. I don't want to touch that new object in case it's going to set me off. I have fear and worry every time I go out, is the food going to be different from what I'm used to and set off the eczema? I carry around the emollients so I can wash my hands everywhere I go. It's extra things to remember. Sometimes in work the air conditioning makes my skin worse. So that makes me worry about going into the office.** ”

In which of the following areas do you experience eczema? Select all that apply



Having eczema on my hands (vs. other areas of the body) is harder because I need to constantly use my hands.





PSYCHOSOCIAL IMPACT

The social stigma of CHE

The research suggests that the impact of CHE goes beyond physical symptoms. The visibility of the condition can lead to social stigma and judgement, which can have an impact on the individual's mental health and social wellbeing. Survey respondents wrote about the impact CHE had on their sense of self, and their perceptions of judgement from others:

“ Makes me so insecure and self-conscious, as if people think I have a disease or I'm disgusting. **I feel ashamed.** ”

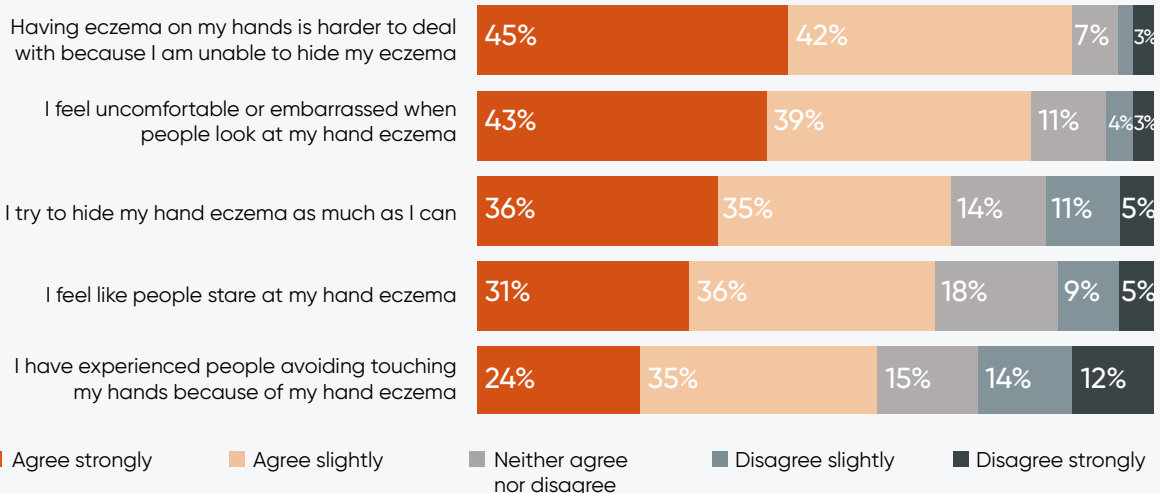
“ It gets me down. I **hate people staring** at me which makes my confidence low. ”

“ It's made me so **self-conscious**, and I avoid seeing people. ”

“ Even though I'm quite a confident person, **it's anxiety inducing to have my hand eczema visible as most don't ask me what it is, they assume I'm unclean or unmoisturised.** Which is not true. A lot of judgement without asking. ”

The majority (87%) felt having eczema on their hands is harder to deal with because they feel they cannot hide their eczema from others. It can be this visible nature of the condition that can lead to individuals being uncomfortable, feeling like people stare and feeling the need to hide or avoid touching others.

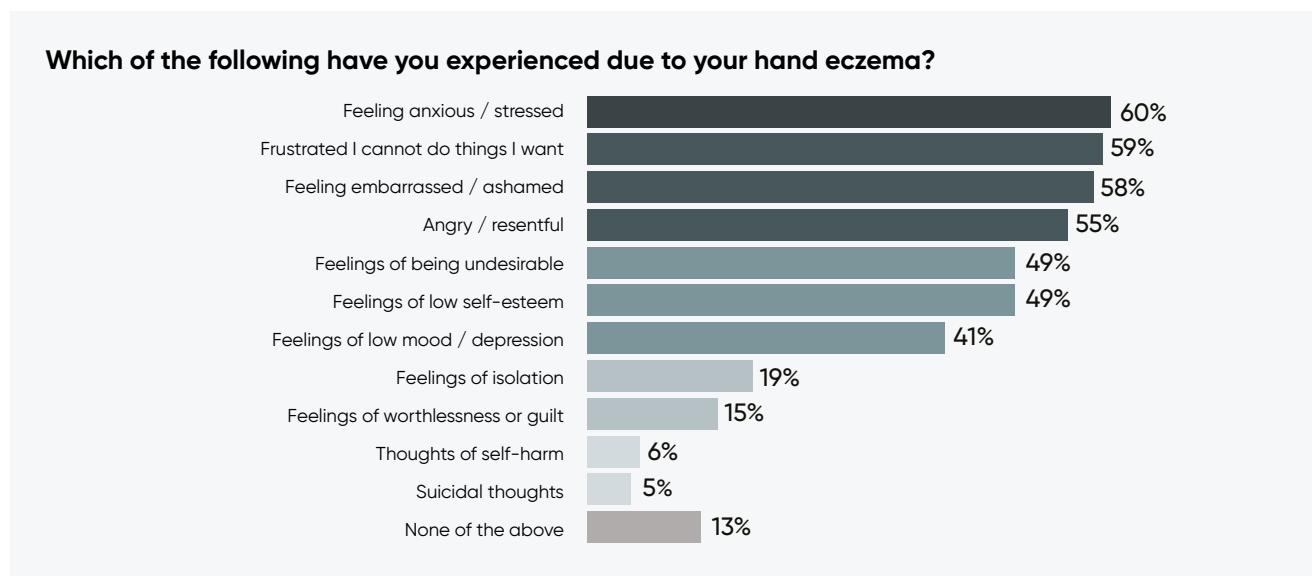
To what extent do you agree or disagree with each of the following statements?



71% agree to some extent that they try to hide their HE as much as they can. For some people living with CHE this can include wearing gloves to conceal their hands from others to avoid judgement. However, this can also create an additional trigger as the gloves can cause the hands to sweat.

Few questions are being asked by HCPs about the impact of CHE on mental health

The most reported emotional impacts due to CHE were feelings of stress, frustration, embarrassment, and anger. 41% reported feelings of anxiety or stress from their CHE either frequently or most days. One in five reported feelings of low mood or depression frequently or every day.



Many felt CHE placed limitations on their lives, with 59% feeling frustrated about things they want to do but can't:

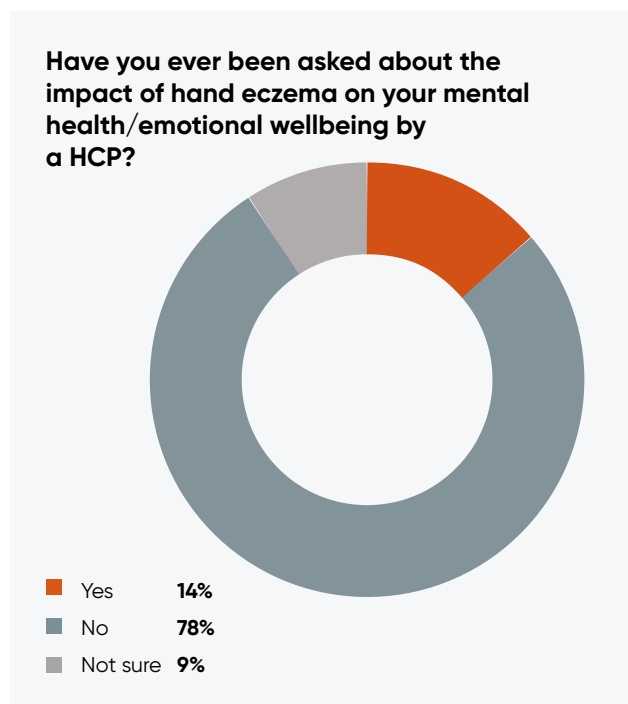
“ A **massive hindrance** to do everyday things, **making me feel handicapped**, not able to use my hands properly. There are days just lifting a teacup is a chore. ”

55% reported feelings of anger or resentment due to their CHE. Within the interviews and survey, people expressed anger towards their condition but also anger towards healthcare support:

“ I don't think the NHS cares about eczema at all. Well, I don't think they understand the **depth of stress it can put on people** and the impact it has on their lives. ”

Despite the sizable impact on social wellbeing and mental health, few respondents reported ever being asked about this by their HCP.

These findings identify the need for HCPs to ask more questions about their patient's emotional wellbeing, enabling them to better understand the burden of CHE faced by their patient and the support needed.





QUALITY OF LIFE & RELATIONSHIPS

CHE has a high impact on quality of life (QoL)

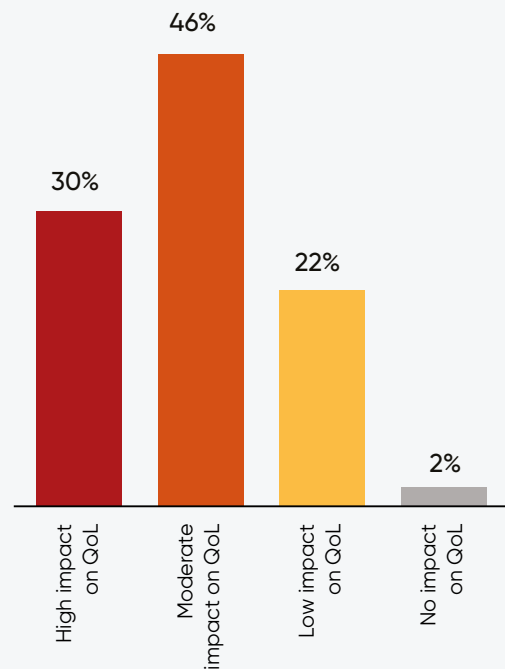
Both physical and psychosocial factors can impact an individual's QoL. In the interviews, respondents described how their whole lives felt defined by their CHE, and it permeated everything they did.

CHE affects peoples' social lives, with 76% agreeing they avoid doing certain hobbies, while 14% said that CHE made them avoid going to social events. When asked about the impact of CHE on their lives, a survey respondent wrote:

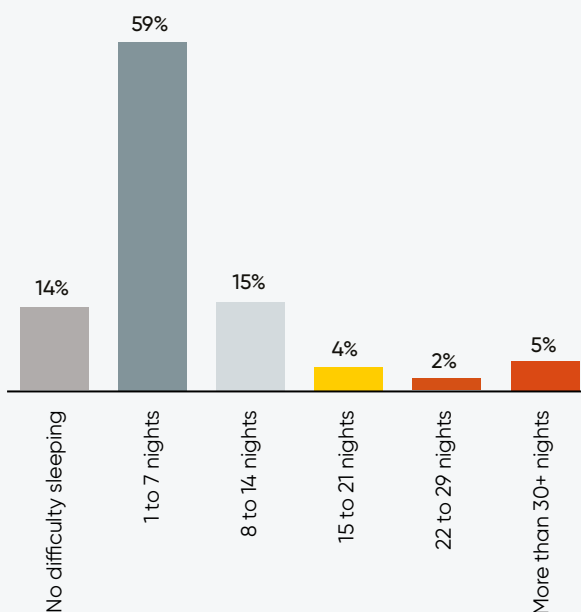
“ When at its worst **I can't cook, clean, wash myself** (very painful) need help of family to **prepare food, do shopping, cleaning.** ”

76% rated the impact of CHE on their QoL as high or moderate, with 89% sharing that their CHE has some impact on their QoL at least most months. Only 2% of respondents stated that CHE has no impact on their QoL.

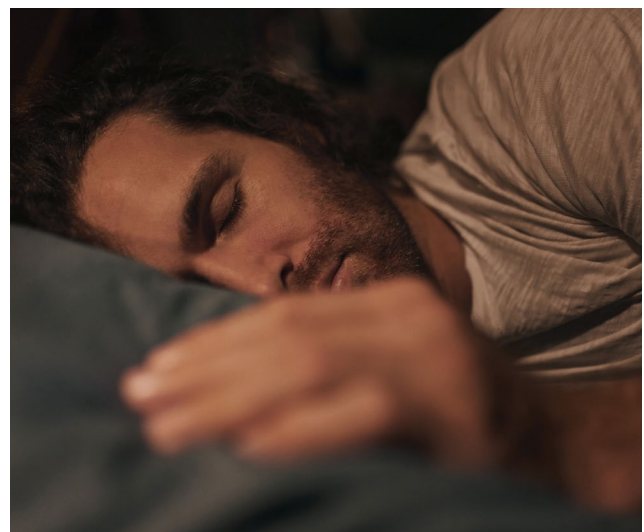
To what extent has hand eczema impacted on your overall quality of life (QoL)?



Thinking back to your last flare, how many nights sleep would you estimate were disturbed due to the itch and/or pain from hand eczema?



Sleeping is often difficult for people with CHE, with the majority (86%) having difficulty sleeping during their last flare. Sleep disturbance caused by eczema itch has been attributed to; daytime fatigue, decreased mental capacity and motor performance and an overall worsening of QoL.⁵





A significant burden on relationships

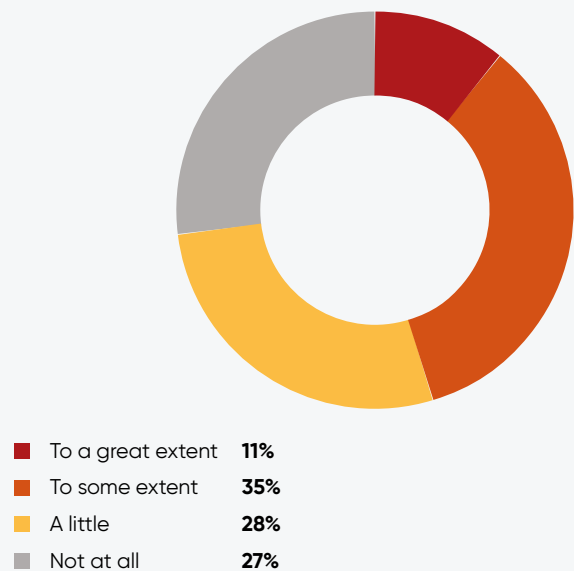
Our hands are also fundamental to how we interact with others, from shaking hands at work, to forming new romantic relationships, and looking after the people we love. So, when we do not have full use of our hands or are trying to hide our hands, it can negatively affect our interpersonal relationships.

Nearly three quarters (73%), reported that CHE has some impact on their existing relationships or created difficulty in their ability to build new ones. Furthermore, just over half (56%) say CHE prevents them from even touching their loved ones. 29% felt unable to care for their family as they would like to, with one mother lamenting:

“ I can't bath my little boy regularly because of my hands and I feel really guilty as **I feel like a bad mum**. It also means that I get anxious about housework as my partner has to do more than me. ”

Several people reported that the challenges of not being able to do housework tasks had an impact on their relationships; 9% said CHE had contributed to tensions with the people they live with. It was revealed that those without CHE struggle to understand the need to avoid tasks or responsibilities. This was reported by a few people who did not live with their immediate family but were living in student accommodation or shared housing arrangements with housemates.

To what extent has hand eczema impacted on your existing relationships or ability to build relationships?



Living with CHE also impacts their sense of self, just under half (49%) are left feeling undesirable and unattractive due to their CHE. 27% are scared to initiate new interactions in case they are rejected due to their CHE.

One survey respondent simply wrote:

“ I feel **untouchable**. ”



IMPACT ON WORK

Most people with CHE are experiencing an impact on their current job

The research demonstrates that CHE impacts some people's ability to work, this is often due to physical symptoms preventing them from doing practical elements of their job but for some it also affects their ability to focus and be productive.

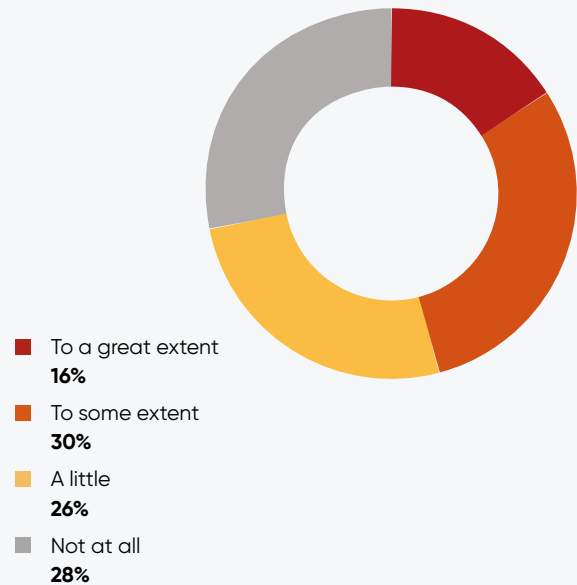
People in certain occupations were more affected by their CHE, particularly those whose occupations that involve prolonged wet work or harmful skin exposure.³ This includes HCPs, who may be required to wash their hands multiple times a day, and those in the service industry including cleaners and waiting staff, who may be exposed to cleaning products, and those in education.



One person described the additional measures they need to take to manage their CHE while working in healthcare:

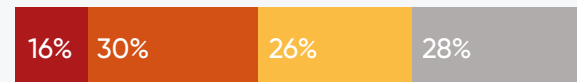
“ I'm training to be an occupational therapist and it **hugely impacts my work** due to having to regularly wash my hands. I get embarrassed as I have to carry a different liquid soap and get questioned on professionalism as I can't use hand sanitizers when entering/leaving the room. This makes me feel really **guilty and uncomfortable**. ”

To what extent, if at all, does hand eczema impact on your current work/education?



There is a greater impact for those in healthcare, service and education industries

Total n=152



HCP (n=24)



Service industry (n=17)



Education (n=14)



- To a great extent
- To some extent
- A little
- Not at all

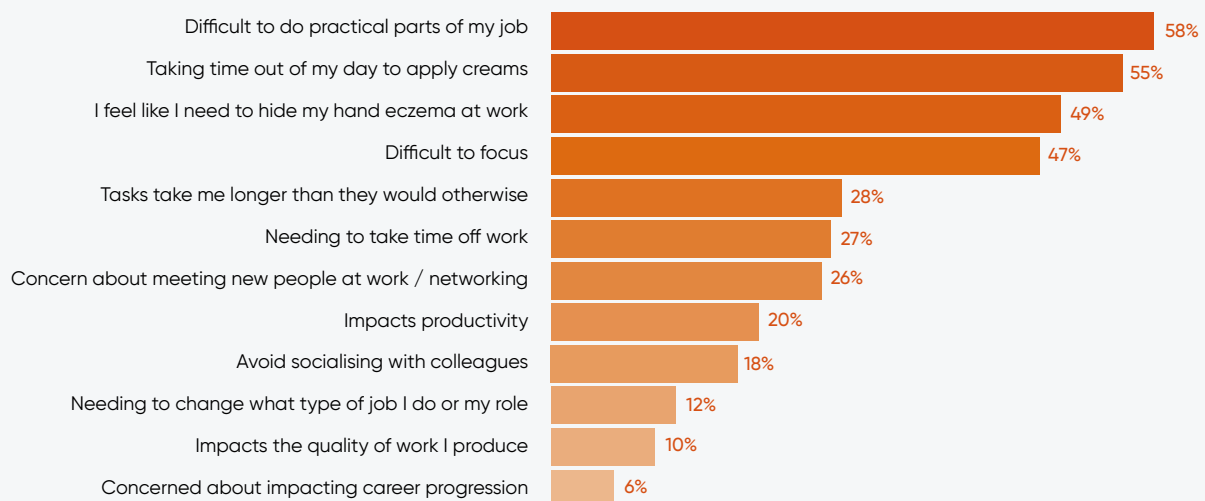
CHE can impact the choice of work and productivity whilst at work

The hands are our primary tool for completing workplace tasks, whether writing, typing, handling products, or operating heavy machinery. It is these tasks that can be a challenge for those living with CHE, with 58% sharing that the condition impacts the practical parts of their job.

Just under half (49%) shared that they felt like they needed to hide their condition from others at work. One of the individuals who was interviewed shared:

“ Working in the private sector I feel like... it's very competitive. **So, I wouldn't want to say anything that's going to give me a disadvantage...** I wouldn't want them to think "oh she's also got this" when they're looking to promote people, for example. ...It is such a competitive environment...I know it would be confidential as well, but I'm not sure. ”

How does hand eczema impact you at work? Select all that apply



The findings also suggest how CHE could affect an individual's work life due to needing to take time off work, and loss of productivity and focus. One respondent described how CHE prevented them from obtaining work altogether:

“ **Very draining, certain jobs and tasks I cannot do, no money due to unemployment or being unemployable. I have to wear gloves most of the time.** ”

This impact on work is experienced by people living with CHE despite over half of respondents (52%) sharing that their CHE had impacted their choice of career or education.

Two respondents described how CHE had prevented them from pursuing a career in healthcare:

“ As a young person, I knew **certain careers** which involved a lot of hand washing – such as nursing – would be **impossible for me**, and that was limiting. I became a teacher but using a chalk board, as we did in those days, triggered my hand eczema. ”

“ **I had to completely change my job in NHS** due to it. Psychologically the impact of changing my career was very difficult. ”



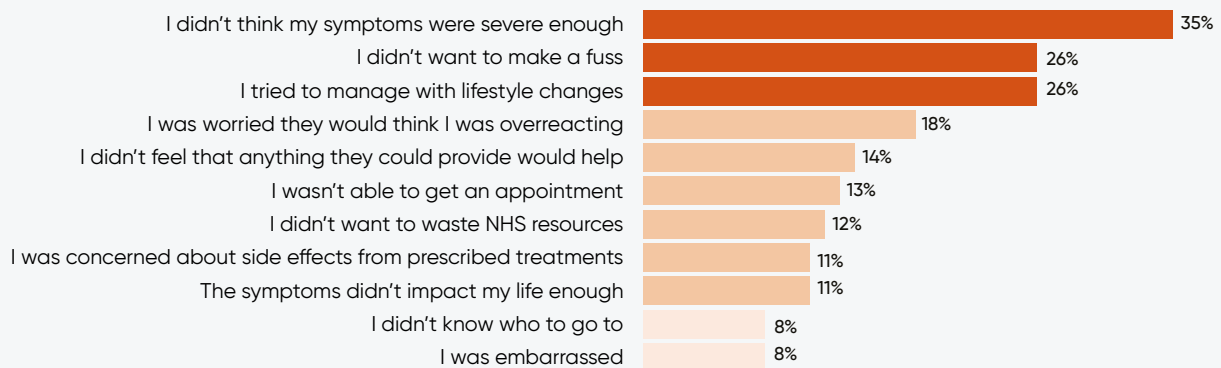
PATIENT HEALTHCARE EXPERIENCE

People living with CHE are delaying seeking healthcare support

Despite the significant physical symptoms, and the impact on their psychosocial wellbeing, QoL, and work, people living with CHE report significant delays in seeking healthcare support. The research found respondents living with CHE waited for a significant amount of time before they sought any help from a HCP – a median time of eight years.

When asked what had prevented them from seeking help earlier, the most common reason for this delay was that they didn't think it was severe enough, didn't want to make a fuss or were trying to use lifestyle changes first. 20% were not currently seeking help from any HCP concerning their CHE.

What, if anything, prevented you from seeking help from a healthcare professional earlier?

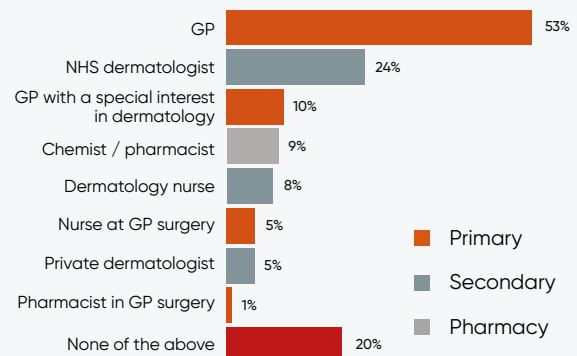


When asked what prompted them to finally seek help, 41% shared that they only sought help when they felt unable to manage their symptoms by themselves anymore. These results highlight how people experiencing CHE often downplay their symptoms and their suffering and expect negative judgements from others, despite it having a significant impact on their life.

Patients are concerned they will be perceived as over-reacting as it is just their hands therefore are reluctant to discuss their eczema or its impact with others – this also creates a barrier to patients accessing support. This is in addition to the fluctuating nature of the condition:

“ I felt like I was making a big deal out of it, perhaps especially because when I went, I remember it wasn't so bad as it had been, and I was showing photos to say “I promise it is really bad”, but it's hard to sometimes see on a photo. So, I think I felt maybe I was making a big fuss. ”

Which of the following healthcare providers are you currently seeking help for your hand eczema?



When people living with CHE do access healthcare the majority of them are being treated by their GP in primary care and 47% are seeking help from them a few times a year.

Despite all respondents to the survey meeting the definition criteria for CHE, only 4% said they had been diagnosed with CHE specifically, all of which had happened in secondary care. The majority (80%) said they had been diagnosed with eczema or atopic dermatitis. 8% had no formal diagnosis.

A need for greater education for HCPs and support for their patients

In interviews it was discussed how people living with CHE can lose faith in the support offered by their HCPs, preventing them from seeking further help from the healthcare system.

“ I think I hadn't gone for my hands because, what are they going to do? **They're not going to do anything. They're just going to give me a steroid and send me on my way.** Which is why I probably had held off on going to the doctor, so I can't be bothered, but especially with COVID, they're not going to someone about something like eczema. ”

Almost all (97%) had been prescribed treatment for their HE by a HCP. However, only a third were currently satisfied with their current treatment options. Furthermore, 35% felt like they had little input into which treatments they received, and 22% felt like they had no involvement at all.

Some respondents shared feelings of hopelessness, 66% agreed to some extent that they will never get control of their CHE.

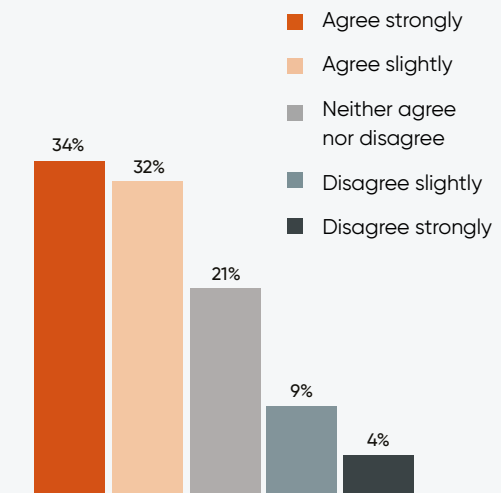
“ I've kind of lost hope with them helping me with my eczema. I just think it's going to be something I have to have forever. ”

When asked what activities, services or support they would like to see provided in relation to HE, 66% of survey respondents said there needs to be more education for HCPs regarding HE.

Furthermore, just over half (56%) want to see more education on the unique challenges of HE vs. general eczema with the hope others would begin to understand CHE better.

The findings identify a need for greater education for HCPs regarding CHE and more support for people living with suspected CHE, to seek healthcare support earlier.

I would like to get more support from my healthcare professional to control my hand eczema.



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